

Selected case studies



A research study on involving people with lived experience into health and social care policy and decision-making

Contents

Case study 1: Learning from lived experience: Scottish Social Services Council	1
Case study 2: Understanding Citizenship Within a Health and Social Care Context in Scotland Using Community-Based Participatory Research Methods.....	3
Case study 3: Engaging people with lived experience. A guide for including people in poverty reduction	6
Case study 4: Raising Refugee Woman’s Voices - Exploring the impact of Scottish Refugee Council works with the Refugee Women’s Strategy Group.....	9
Case study 5: The role of lived experience in creating systems change	12
Case study 6: Poverty and Ethnicity - Agenda and Policy Development in Scotland– Lived experience of Ethnic and Cultural Minority Communities	15
Case study 7: Engaging People with Lived Experience: A Toolkit for Organizations.....	17
Case study 8: Co-production case study - RSRFL Glasgow Peer Research Project	20
Case study 9: Lived Experience Influence and Participation Policy: Ensuring that people with mental health problems drive all that we do	22
Case study 10: From ‘they’ to ‘we’. Reflections on working as lived experience advisors.....	24
Case study 11: Engagement Factsheet 2. Effective Engagement.....	26
Case study 12: MH:2K Final Evaluation Report FINAL.....	28
Case study 13: The Value of Lived Experience in Social change: The Need for Leadership and Organisational Development in the Social Sector	30
Case study 14: Guide 3: Involving people with lived experience of mental health problems in the design and delivery of your work.....	32
Case study 15: Are people with lived experience of poverty finally being heard?	35
Case study 16: Patient participation as an integral part of patient-reported outcomes development ensures the representation of the patient voice: a case study from the field of rheumatology	37

Case study 1: Learning from lived experience: Scottish Social Services Council

<p>Organisation and authors</p>	<p>Scottish Social Services Council</p>
<p>Year</p>	<p>2019</p>
<p>Purpose</p>	<ul style="list-style-type: none"> • Learning from lived experience for social services to be improved through strategic planning with people with lived experience. • This plan is for anyone with lived experience of social services, carers, organisations, our staff, communities who want to get involved in work that will develop and improve the social service workforce, enabling people who work in these vital services to deliver the highest quality of care, with the skills, compassion and values that result in the best outcomes for our citizens.
<p>Why is this case study useful?</p>	<ul style="list-style-type: none"> • As a health and social care regulator in Scotland, planning for including lived experience. • Intending to have an impact on people with lived experience, the people who work with SSSC and to the organisation.
<p>LO1. Best practices in engaging people with lived experience:</p>	<ul style="list-style-type: none"> • Co-producing together • Engaging • Consulting • Informing
<p>LO2. Barriers and enablers in engaging people with lived experience in decision-making and policy</p>	<div style="background-color: #d9d9d9; height: 100px;"></div>

LO3. What does inclusive and meaningful participation mean to practitioners and participants themselves?

"The value of involvement can include knowledge exchange, to connect to peer support and learning, to help reduce isolation, connect to information and community resources, contributing to personal and professional development. Involvement can have a positive impact on wellbeing, empowering people and communities. Involvement is also important in collaborating for on-going improvement and planning together for the future." (p.4)

- Increase confidence
- Increase connections

LO4. Impact/benefits on policy and decision-making of engaging people with lived experience

- Knowledge (better understanding of complexities of social care)
- Effective policies tailored to different realities

Link to document

https://www.sssc.uk.com/_entity/annotation/98d2b10f-d311-77f2-8c6a-2c5bc9251386



Case study 2: Understanding Citizenship Within a Health and Social Care Context in Scotland Using Community-Based Participatory Research Methods

<p>Organisation and authors</p>	<p>Gillian MacIntyre, Nicola Cogan, Ailsa Stewart, Neil Quinn, Michael Rowe, Maria O’Connell, Duncan Easton, Linda Hamill, Michael Igoe, Gordon Johnston, Anne-Marie McFadden & John Robinson SAGE Research Method case</p>
<p>Year</p>	<p>2018</p>
<p>Purpose</p>	<p>Community-based participatory research principles were used to develop a conceptual framework of citizenship for people experiencing mental health problems and/or other life-disrupting events in Scotland. This case study illustrates the use of a participatory methodology replicating an approach adopted as part of an international collaboration in understanding citizenship across diverse social and cultural contexts.</p>
<p>Why is this case study useful?</p>	<ul style="list-style-type: none"> • Involving peers at every stage of the process • Open communication with all partners at every stage of the process • Aims to Develop a conceptual model of citizenship that could be applied in policy and practice in Scotland • Work with a co-research team of people with lived experience (peer researchers) using a CBPR approach • Understand some of the issues faced by persons experiencing mental health problems and/or other life-disrupting events • Appreciate the challenges in defining and facilitating discussion around a complex concept such as citizenship • Understand the importance of using community-based participatory research methods involving peer researchers

- Recognize the value in bringing together the perspectives of people with lived experience, policy makers, and practitioners
- Understand some of the challenges, and opportunities, of undertaking participatory research involving peer researchers
- Consider potential adaptations to methods used to “meaningfully” engage participants with diverse needs and experiences

LO1. Best practices in engaging people with lived experience:

When researching or working with people with lived experience

- We also had to ensure that we had a shared understanding around language, particularly in relation to key concepts used, including the terms “citizenship” and “life disruption” as subtle differences in language could have had significant consequences for how concepts were understood. Maintaining a regular dialogue, checking for any potential miscommunications or differences in understanding, and being open to diversity in opinions were key strategies to maintaining a strong working alliance.

Preparation & training

- Training in research methods was then provided. The training covered a range of areas including
- An overview of the project and the work that had previously been carried out by our colleagues in Yale
- An overview of different research methods including the use of focus groups and concept mapping and consideration of the pros and cons of these
- The opportunity to practice facilitating focus groups sessions via role-plays
- Consideration of some of the key ethical issues and dilemmas involved in research of this nature
- Consideration of how to deal with conflict and how to manage “difficult” research participants

- Positioning oneself within the research process through identifying our own opinions, experiences, and biases
- Consideration of the importance of confidentiality and appropriate data management processes

Insider vs outsider status

Reflexive approach

Compensation for peer researchers

LO2. Barriers and enablers in engaging people with lived experience in decision-making and policy

Barriers/challenges

- the organisation must have sufficient resources and time to meaningfully engage
- can be very lengthy and time consuming & resource intensive
- organisations need to have a reflective stance in order to recognise blind spots (for example jargon and language)
- difficult to involve peer researchers meaningfully in data analysis phase

LO3. What does inclusive and meaningful participation mean to practitioners and participants themselves?

- The involvement of peer researchers reduces unequal power relationships between the researchers and the research participant

LO4. Impact/benefits on policy and decision-making of engaging people with lived experience



Link to document

<https://demsoceu.sharepoint.com/:b:/s/RedearchandDesign/EVCynLFjFzZlvmcyjo2s18BlpTGUQZalrmUB5dvisRzCA?e=gTbhtP>

Case study 3: Engaging people with lived experience. A guide for including people in poverty reduction

Organisation and authors	Tamarack Institute Alison Homer
Year	2019
Purpose	Recommendations for ways to involve people with lived experience of poverty in decision-making processes.
Why is this case study useful?	In addition to being a resource in itself, it includes ten additional case studies that give examples of involving people with lived experience in projects.
LO1. Best practices in engaging people with lived experience:	<ul style="list-style-type: none"> • Take time to build trust • Commit to engage with people with lived experience • Advocate for inclusion • Share power
LO2. Barriers and enablers in engaging people with lived experience in decision-making and policy	<p>Enablers:</p> <ul style="list-style-type: none"> • Host accessible meetings • Create opportunities for engagement • Eliminate financial barriers to participation • Consider paying people with lived/living experience for their time • Provide training and mentoring opportunities <p>Each bullet point had further detail of best practice for this</p>

Barriers:

- Power imbalances (practitioners in leadership positions can dominate agendas and decisions)
- Financial

LO3. What does inclusive and meaningful participation mean to practitioners and participants themselves?

(p.42)

- Commit to engaging people with lived experience
- Create a culture of inclusion
- Recruit people with lived/living experience
- Design meetings with people in mind
- Compensate participation-related expenses
- Create opportunities to engage
- Build capacity
- Set goals
- Diversify representation

LO4. Impact/benefits on policy and decision-making of engaging people with lived experience

Benefits:

- People with lived/living experience deeply understand the realities of issues and their experiences service as powerful tools for building understanding, root causes and scope.
- Lived experience first-hand knowledge of systemic barriers is invaluable in co-creating innovative solutions.

Case study yapc.ca (whitehorsa)

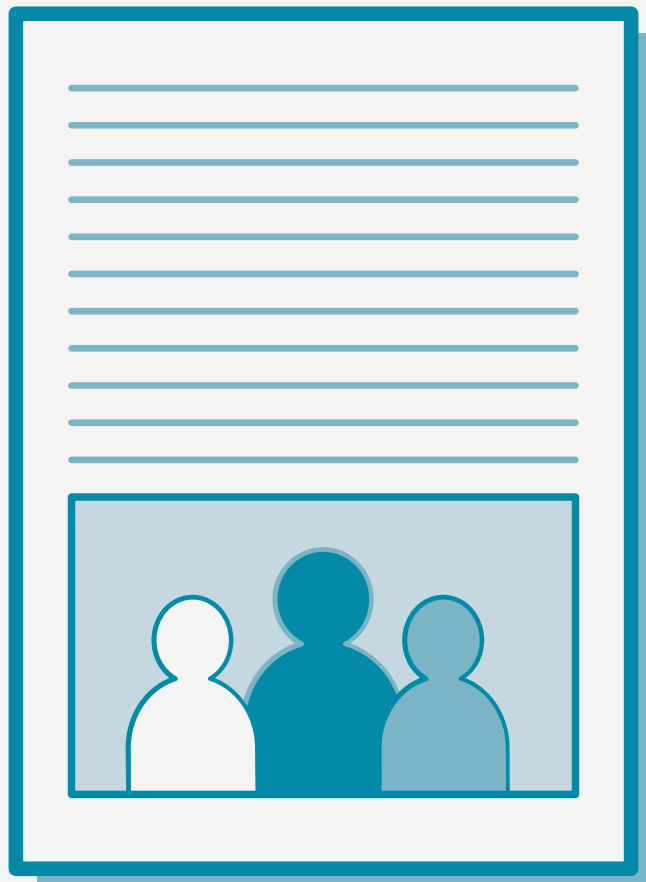
"Successes of the program's design include: having a co-facilitator with lived/living experience; hosting open discussions; and being flexible, responsive, and willing to adapt based on the strengths and assets that participants bring to the table. Graduates have expressed that the program has helped them know where to start on their healing journeys, how helping

others has helped them, as well, and how they have been inspired to say and do more in the name of eradicating poverty.

Fourteen individuals were trained through the first two cohorts of the program, nine of whom remain passionately involved. Three trainings are planned for 2019, with the first receiving three times as many applications as spots available. As the community has grown familiar with the program, graduates have been increasingly called on by external partners to tell their stories and to provide advice." (p.29)

Link to document

<https://www.tamarackcommunity.ca/hubfs/Resources/Publications/10-Engaging%20People%20With%20LivedLiving%20Experience%20of%20Poverty.pdf>



Case study 4: Raising Refugee Woman’s Voices - Exploring the impact of Scottish Refugee Council works with the Refugee Women’s Strategy Group.

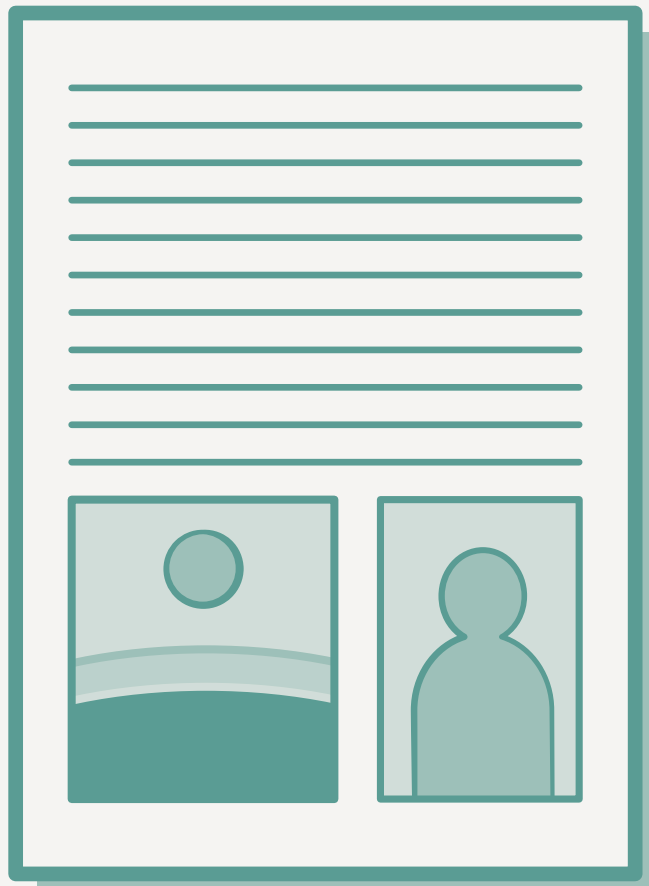
<p>Organisation and authors</p>	<p>Scottish Refugee Council</p> <p>Melanie Quintero, Nina Murray, Elaine Connelly and Fiona Ballantyne</p>
<p>Year</p>	<p>2015</p>
<p>Purpose</p>	<p>Partitioner case study examining the impact of the work of the Refugee Women’s Strategy Group policy influencing and advocacy with a purpose to bring social change. It worked to empower refugee and asylum-seeking women in Scotland to have their voices heard by decision makers and to influence the policy and practices impacting on their lives.</p>
<p>Why is this case study useful?</p>	<p>This case study showcases the impact the RWSG work combining community development with policy influencing and advocacy. This project sought to combine its policy influencing and advocacy with a purpose to bring social change. It worked to empower refugee and asylum-seeking women in Scotland to have their voices heard by decision makers and to influence the policy and practices impacting on their lives.</p> <p><i>“We can say these are the lived experiences of women, they are irrefutable, they are not anecdotal, they are not hearsay, they are real, they are lived, the actual. I think there is tremendous power in that” (p.12)</i></p>
<p>LO1. Best practices in engaging people with lived experience:</p>	<ul style="list-style-type: none"> • The project used a community development approach ensuring that they supported participants to create a strong community approach to both guide work and create a legacy for refugee communities. • Combined policy influence and advocacy with community development in ways to identify needs, organise action and tackle inequalities.

	<ul style="list-style-type: none"> • Skilled community development support was crucial (External stakeholders also identified the importance of the approach adopted by the women’s project, recognising the uniqueness and effectiveness of the model).
<p>LO2. Barriers and enablers in engaging people with lived experience in decision-making and policy</p>	<ul style="list-style-type: none"> • Barriers to meaningful participation of in decision that affect them such as the value that is placed on their involvement and the willingness of agencies to develop and sustain equal partnerships. • The stress of participants lived experience can affect the ability of woman to participate in the work/ decision-making.
<p>LO3. What does inclusive and meaningful participation mean to practitioners and participants themselves?</p>	<p>Participants:</p> <ul style="list-style-type: none"> • Due to being involved in this project they became more integrated into their local community. • Because of the strong community development approach woman spoke of feeling ‘qualified’ to take other roles in the community due to skills and knowledge gained from taking part. It also opened up other opportunities for woman. • Ensuring that participants gain something from being involved such as skill development (computer skills, communication skills, English language skills, teamwork, analytical skills etc).
<p>LO4. Impact/benefits on policy and decision-making of engaging people with lived experience</p>	<ul style="list-style-type: none"> • Although hard to pinpoint participants felt the asylum process was better in Scotland because of the work of the group. • The group plays a key role in Scotland's refugee integration strategy • Affecting measurable policy change in this area is particularly challenging, as it is heavily politicised and subject to rapid and complex shifts at the whim of governments of the day. • Through the community development approach, the group has created a strong platform for refugee women to campaign their rights.

- The benefits to policy from this work are that the asylum process will be more gender sensitive (The work influenced policy change and childcare for asylum was introduced, Examples of other areas of improvement in practice include; gender training for decision makers, inclusion of asylum specific actions in the Home Secretary's Call to End Violence Against Woman and Girls (p.15)

Link to document

https://www.scottishrefugeecouncil.org.uk/wp-content/uploads/2019/10/Scottish-Refugee-Council_s-Women_s-Project-Impact-Report.pdf



Case study 5: The role of lived experience in creating systems change

<p>Organisation and authors</p>	<p>CFE Research</p>
<p>Year</p>	<p>2020</p>
<p>Purpose</p>	<p>To look at ways in which people with lived experience of multiple disadvantage create system change and the impact of their involvement.</p> <p><i>"Potentially the most powerful way for experts to create a lasting difference is through directly influencing the design and delivery of policy and services. Involving experts in gathering and sharing evidence from current service users and planning new services or initiatives helps ensure services are designed to meet the needs and preferences of people affected by multiple disadvantages. Experts provide a powerful and authentic voice and unique insights that can challenge assumptions, motivate organisations to do things differently and pinpoint areas for change" (p.3)</i></p>
<p>Why is this case study useful?</p>	<p>This study gives examples of several policy and practice changes as a direct result from learning and input from people with lived experience. It also details inclusive and meaningful practices and examples of co-production.</p>
<p>LO1. Best practices in engaging people with lived experience:</p>	<ul style="list-style-type: none"> ● Creating a sense of community. This leads to a supportive environment when people with lived experience are involved ● Being mindful that participants are not just 'Lived experience' and that they have other skills and attributes to contribute ● Ensuring that lived experience activities (such as peer research, awareness raising events, co-production) target and reach those who can gain the most from the outcomes. For example, targeting organisations/officials with a lack of understanding/awareness/need changed rather than those who are already knowledgeable

- Ensuring that lived experience activities result in **convincing evidence** to help improve and influence policy and practice. Peer Research/Gathering evidence a good example of this
- That organisations working with lived experience accurately represent the voice and experiences of lived experience
- Ensuing that before a co-production event, lived experience participants have sufficient information about the purpose of the activity (to reduce isolation/ anxiety)
- Organisations need to support lived experience well
- Ensure involvement of lived experience isn't tokenistic

LO2. Barriers and enablers in engaging people with lived experience in decision-making and policy

Barriers:

- Can at times be a tick box exercise rather than implementing any change in decision-making and policy
- At times not taken as seriously as traditional research.
- Organisations need to consider and monitor the potential risk or harm to participants and participants must not feel pressured or expected to share personal stories
- If policy/decision making is not impacted after involvement with lived experience, why would they contribute time/effort in the future

Enablers:

- Organisations need to have an understanding that the typical 9-5 might not work for those with lived experience so should look to engage outside the hours
- Having an informal meeting before the event to find out what participants feel comfortable with is important to safeguard
- Ensure there is a clear understanding of what the task is about

	<ul style="list-style-type: none"> • Provide a safe space for experience to be shared • Offer comprehensive training
<p>LO3. What does inclusive and meaningful participation mean to practitioners and participants themselves?</p>	<p>To practitioners:</p> <ul style="list-style-type: none"> • Accurate information on what best works for people with lived experience • Meaningful ways to improve services/policies <p>To participants:</p> <ul style="list-style-type: none"> • Lived experience participants felt that they were giving back to society in a meaningful way • Power for participants to feel recognised and that their actions and words are being listened to and have a positive effect
<p>LO4. Impact/benefits on policy and decision-making of engaging people with lived experience</p>	<ul style="list-style-type: none"> • Participants in the study felt that they had more of a direct impact when contributing to the design and delivery of policy and services rather than being involved in research activities • Examples of lived experience participants having permanent positions on committees and strategic boards ensuring that the lived experience perspective is an ongoing and formalised part of the policy and decision-making • Notes that changing policies and strategies can take a long time to achieve and involve many different actor
<p>Link to document</p>	<p>https://www.bht.org.uk/wp-content/uploads/2021/03/The-role-of-lived-experience-in-creating-systems-change-2020-1.pdf</p>

Case study 6: Poverty and Ethnicity - Agenda and Policy Development in Scotland– Lived experience of Ethnic and Cultural Minority Communities

<p>Organisation and authors</p>	<p>BEMIS</p>
<p>Year</p>	<p>2016</p>
<p>Purpose</p>	<p>Ethnic Minorities (Polish, African, Asian, Caribbean or Black and other ethnic groups) disproportionately live in the most deprived circumstances.</p> <p>BEMIS consulted Ethnic Minority communities in Scotland on issues of social, economic, democratic and cultural policies. Communities themselves were asked to identify the barriers to progressing or escaping poverty. Focused on the relationship between 'poverty and ethnicity'.</p>
<p>Why is this case study useful?</p>	<p>Across Scotland: Glasgow, Dundee, Aberdeen and Inverness.</p> <p>BEMIS and community organisations made recommendations to issues identified by the individuals by looking at the current policy landscape. The first consultation described each community's issues: wide range of issues from housing to education to representation.</p> <p>The second consultation made recommendations identifying the issues, solutions, key stakeholders, authorities and the extent of the action.</p>
<p>LO1. Best practices in engaging people with lived experience:</p>	<ul style="list-style-type: none"> ● Consultations took place in community hubs/ meetings- utilised by the groups themselves ● Identified issues and drafting recommendations and policies with the affected communities through community organisers

LO2. Barriers and enablers in engaging people with lived experience in decision-making and policy

Barriers:

- Employment- immigration status, lack of access to social security
- Lack of premises for cultural services
- Language barrier
- Isolation
- Racism

Enablers:

- To increase availability of childcare
- In depth research by the Nepalese community into experiences

LO3. What does inclusive and meaningful participation mean to practitioners and participants themselves?

To participants:

- Develop culturally sensitive events to foster cohesion and engagement

LO4. Impact/benefits on policy and decision-making of engaging people with lived experience

- To increase cultural sensitivity
- Acknowledgement of the diverse communities in Scotland and the difficulties they face

Link to document

<https://bemis.org.uk/PDF/bemis-poverty-and-ethnicity.pdf>

Case study 7: Engaging People with Lived Experience: A Toolkit for Organizations

Organisation and authors	Suicide Prevention Resource Center (SPRC)
Year	2020
Purpose	<p>As explained by the SPRC in the toolkit homepage: "This toolkit has been developed to assist organizations and agencies leading suicide prevention programs in their communities with recruiting and engaging individuals with lived experience. It may also be useful for other organizations and agencies working in suicide prevention and care."</p>
Why is this case study useful?	<p>This is a detailed toolkit which covers in detail not only how to recruit and involve people with lived experience but also the benefits it has for individuals with lived experience themselves as well as organisations. It also discusses the different levels of engagement, which addresses research questions relevant for this study such as the meaningfulness/quality of inclusion and impact. It also includes a list of tools, such as an example of an announcement to recruit internal staff with lived experience to participate on a suicide prevention project or an application for a person with lived experience to a community Advisory Board application.</p>
LO1. Best practices in engaging people with lived experience:	<p>Engagement ladder</p> <ul style="list-style-type: none"> • Equal input in decision-making processes and access to organisational resources, with added resources and assurances for people with lived experience to equally participate. • Incorporating the lived experience of employees as an organisational central value, including lived experience as a qualification for hiring or participation in project.

- Creating a welcoming environment that allows for different experiences to be discussed and integrated into internal communications and community programming. community organisers

LO2. Barriers and enablers in engaging people with lived experience in decision-making and policy

Barriers:

- Initial resistance in the organisation to change
- Need for resources

Enablers for engaging people with lived experience:

- Training staff and adapting the organisational culture so that it can integrate lived experience (through modelling, expectation setting)
- Accountability, such as holding staff accountable for any inadvertent or subtle discriminatory acts or language)
- Enough resources for inclusive recruitment (such as recruiting people with lived experience as employees)
- Setting expectations, and a welcoming environment.

LO3. What does inclusive and meaningful participation mean to practitioners and participants themselves?

To practitioners:

- Equitable Workplace: authenticity, humanise process
- Quality Improvement: relevant policies, inspire others
- Staff Development: skills, knowledge on topic
- Community Engagement: reflect needs of people with lived experience

To participants:

- Professional Development: skills, networks, leadership
- Personal Development: empowerment, confidence
- Community Advocacy: reduce prejudices, collaboration
- Social Network: support, relationships

LO4. Impact/benefits on policy and decision-making of engaging people with lived experience

- Organization's growth and ongoing improvement through the sets of skills and knowledge that comes with lived experience.
- Reduction in prejudice and discrimination
- Improvements in policies and procedures, which also related to reduced work costs and increased venue
- Improved employee loyalty and morale
- Improvements in the knowledge and attitudes of other staff within the organization, with more sensitivity to community issues and cultural factors.

Link to document

<https://www.sprc.org/livedexperiencetoolkit/about>



Case study 8: Co-production case study - RSRFL Glasgow Peer Research Project

Organisation and authors	British Red Cross
Year	2019
Purpose	Looked at the extent to which asylum-seekers can exercise their rights and access support mechanisms in Scotland. Looked at if individuals could access accommodation and financial support from the Home Office.
Why is this case study useful?	Collaboration with peer researchers, where they conducted the interviews and focus groups with asylum-seekers and co-developed the research project.
LO1. Best practices in engaging people with lived experience:	<ul style="list-style-type: none"> • Peer research created a sense of agency for people who are often deprived from making decisions about their life • Peer researchers were involved in all stages of research from developing the research, interviewing and analysing the results • Accounted for the balance of power in research
LO2. Barriers and enablers in engaging people with lived experience in decision-making and policy	
LO3. What does inclusive and meaningful participation mean to practitioners and participants themselves?	<ul style="list-style-type: none"> • Account for gender of peer educators • Recognise the role and skills peer researchers gained from the experience

- Co-design with peer researchers
- Peer researcher enjoyed doing it and it helped in their own journeys
- Peer researcher did mention wanting to have more formal training on topics

LO4. Impact/benefits on policy and decision-making of engaging people with lived experience

Link to document

<https://communityengagementhub.org/wp-content/uploads/sites/2/2020/04/Peer-research-%E2%80%93-Glasgow.pdf>



Case study 9: Lived Experience Influence and Participation Policy: Ensuring that people with mental health problems drive all that we do

Organisation and authors	Mind
Year	2017
Purpose	Policy document on the importance of lived experience participation and influence, highlighting that opportunities are accessible to a diverse group of people. Policy for those providing support to people experiencing mental health problem(s).
Why is this case study useful?	Clearly describes the different meanings of lived experience: participation, influence and leadership. Outline the ways in participants are paid, represented in their activities and how Mind works.
LO1. Best practices in engaging people with lived experience:	<ul style="list-style-type: none"> • People are accounted for in every aspect of Mind’s work through research, volunteering, campaigning, fundraising • Risk-assessment: Adequate support for those sharing their experiences, consent • Engaging regularly with people with mental health problems at all stages: priority setting, planning, delivery and review
LO2. Barriers and enablers in engaging people with lived experience in decision-making and policy	<p>Enablers:</p> <ul style="list-style-type: none"> • Promoting opportunities to be involved • Reduce barriers of participation- meet people at their places, rather than then coming to see Mind • Paying participants for their time- transportation cost, accommodation, food

LO3. What does inclusive and meaningful participation mean to practitioners and participants themselves?

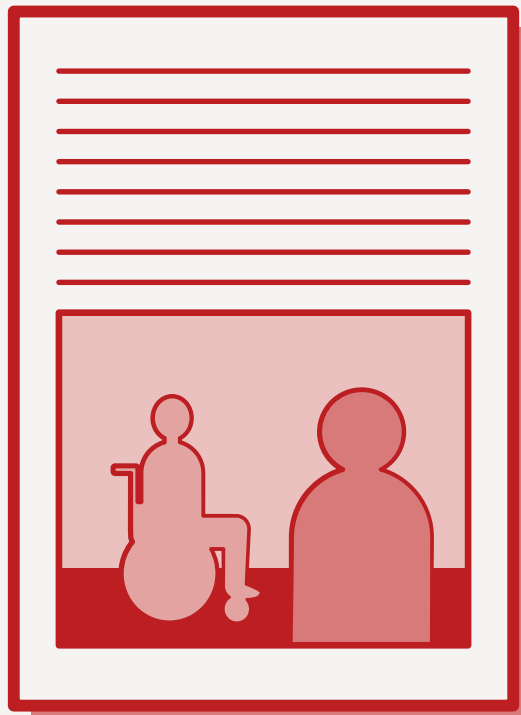
- Everyone's experience is different and have to seek out opportunities to engage with everyone in an inclusive way
- Working together with everyone involved
- Information is more useful
- Practice skills and develop new ones
- Confidence in engaging with organisations

LO4. Impact/benefits on policy and decision-making of engaging people with lived experience

- Projects and services become more effective at accounting for different needs
- Representation of diverse audiences

Link to document

<https://www.mind.org.uk/media-a/4743/mind-lived-experience-influence-and-participation-policy.pdf>



Case study 10: From 'they' to 'we'. Reflections on working as lived experience advisors

Organisation and authors	Samaritans
Year	n.d.
Purpose	A report on the principles for ensuring meaningful and appropriate engagement of people with lived experience in advisory roles. It highlights the challenges and learnings of the project.
Why is this case study useful?	Researchers at Samaritans and lived experience advisors worked together on the report and the research project. Describes the steps in which way to work with people with lived experience of self-harm.
LO1. Best practices in engaging people with lived experience:	<ul style="list-style-type: none"> • Supporting people with lived experience- consider welfare, availability to talk • Empowerment- being listened to, can challenge existing practices, having a voice to influence care they get • Account for individual experiences • Not tokenistic • Advisors- level of professionalism- "real" job • Advisors participating at each stage of process • Provide training • Using accessible and sensitive language • Co-production with advisors- what questions to have and not to have

LO2. Barriers and enablers in engaging people with lived experience in decision-making and policy



LO3. What does inclusive and meaningful participation mean to practitioners and participants themselves?

- Consider different perspectives and experiences
- To participants:
- Able to discuss self-harm with loved ones
- Deconstruct stigma
- Skills development- shaping research questions, facilitate workshops, boost confidence, coaching skills
- Empowerment- being listened to, can challenge existing practices, having a voice to influence care they get

LO4. Impact/benefits on policy and decision-making of engaging people with lived experience



Link to document

https://media.samaritans.org/documents/Lived_experience_advisor_FINAL_I7MmpzN.pdf

Case study 11: Engagement Factsheet 2. Effective Engagement

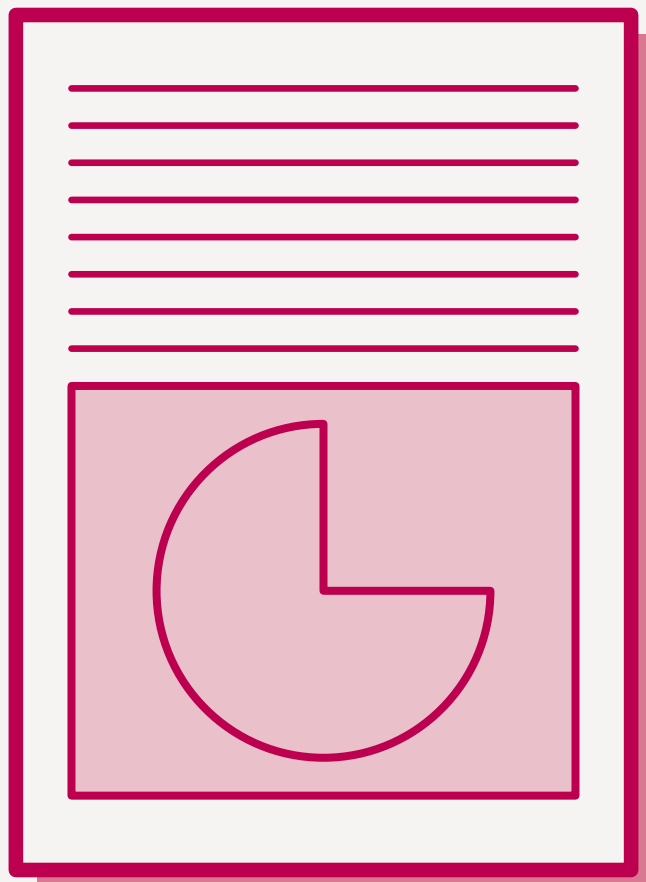
Organisation and authors	Activity Alliance
Year	n.d.
Purpose	The document describes some ways in which to engage disabled people in sport or active recreation. It emphasises that the process must be inclusive and accessible.
Why is this case study useful?	Has an engagement ladder which can help in planning engagement with disabled people.
LO1. Best practices in engaging people with lived experience:	<ul style="list-style-type: none"> • Have to understand who, why, when and how to target audiences • Consider geographical areas before planning • Networks- existing organisations that work in sports • Location accessibility- venue for event needs to be accessible • Accessible communication • Measure and share impact of project • Sustainability- embed learning and findings from project
LO2. Barriers and enablers in engaging people with lived experience in decision-making and policy	

LO3. What does inclusive and meaningful participation mean to practitioners and participants themselves?

LO4. Impact/benefits on policy and decision-making of engaging people with lived experience

Link to document

https://www.activityalliance.org.uk/assets/000/002/883/Engagement_factsheet_2_-_Effective_Engagement_original.pdf?1557928886



Case study 12: MH:2K Final Evaluation Report FINAL

Organisation and authors	MH:2K
Year	2017
Purpose	MH;2K offered a model for engaging young people in issues and solutions relating to mental health in their local area.
Why is this case study useful?	Citizens (Citizen researchers) are the centre of the project. They design events to engage a wider group of local young people on mental health issues. They also co-create the recommendations with experts (researchers and local decision makers). Finally, the citizens present the outputs of the project to local and regional stakeholders.
LO1. Best practices in engaging people with lived experience:	<ul style="list-style-type: none"> • Created a safe space for participants to share views • Giving young people a platform to share their views with officials • Use their own experiences to explore mental health drivers and impacts • Engage small group of young people who then engage with larger audience of young people on issues of mental health • Encouraging collaboration between participants and local partnerships • A well thought out and designed co-production event. • Having a diverse range of young people involved • Meeting diverse range of peers

LO2. Barriers and enablers in engaging people with lived experience in decision-making and policy

- Challenges for young people to be involved due to work or school commitments
- More updates between meetings

LO3. What does inclusive and meaningful participation mean to practitioners and participants themselves?

- Confidence in understanding mental health
- Subtle examples of impact such as feeling more relaxed in group situations
- Personal wellbeing or future aspirations as a direct result of taking part
- Having increased knowledge and overall confidence as a direct result of taking part in the process
- New skills (in teamwork and discussions)

LO4. Impact/benefits on policy and decision-making of engaging people with lived experience

- Possible creation of Task and Finish group- including MH:2K expert panel members

Link to document

https://s3.amazonaws.com/participedia.prod/20f033ef-756c-4da3-9335-177b26bd36b1_MH2K-Oldham-final-evaluation-report.pdf

Case study 13: The Value of Lived Experience in Social change: The Need for Leadership and Organisational Development in the Social Sector

Organisation and authors	The Lived Experience Baljeet Sandhu
Year	2017
Purpose	Looks at how the social sector develops its social impact work through the work of experts.
Why is this case study useful?	Value of lived experience in social purpose organisations.
LO1. Best practices in engaging people with lived experience:	<ul style="list-style-type: none"> • Lived experience as the key concept in social change • Creating equitable opportunities- funding
LO2. Barriers and enablers in engaging people with lived experience in decision-making and policy	<ul style="list-style-type: none"> • Not focused on facilitating- focused on pre-planned programmes • Tokenistic • Problems in recognising inequalities, fail to provide communities ownership for change • Fail to share power • Language and stigma- language used to describe lived experience (victims, service user) • Lack of awareness of the value of lived experience • Lack of funding • Lack of inclusive opportunities- expect people to volunteer, lack of paid opportunities

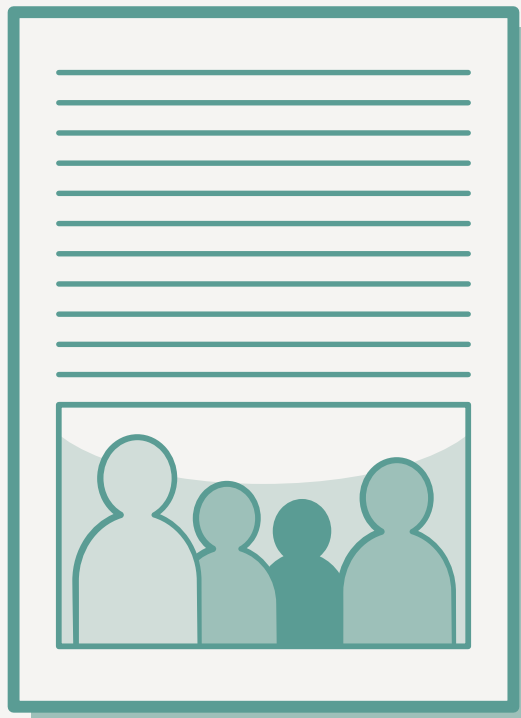
LO3. What does inclusive and meaningful participation mean to practitioners and participants themselves?

- Strengthens the legitimacy of social purpose work
- Improves the effectiveness of services and social change initiatives
- Enhances community cohesion and effective partnership
- Innovation

LO4. Impact/benefits on policy and decision-making of engaging people with lived experience

Link to document

<https://www.thelivedexperience.org/wp-content/uploads/2017/07/The-Lived-Experience-Baljeet-Sandhu-VLE-summary-web-ok-2.pdf>



Case study 14: Guide 3: Involving people with lived experience of mental health problems in the design and delivery of your work

<p>Organisation and authors</p>	<p>Mind</p>
<p>Year</p>	<p>n.d.</p>
<p>Purpose</p>	<p>A guide to the ways in which people with lived experience of mental health problems can be involved in organisation's work.</p>
<p>Why is this case study useful?</p>	<p>Includes a participation ladder which describes the different levels of involvement. Gives examples of successful initiatives involving people with lived experience of mental health problems.</p>
<p>LO1. Best practices in engaging people with lived experience:</p>	<ul style="list-style-type: none"> ● First consulting people with lived experience ● Working together with fixed roles ● Working on common objectives ● Contributing to decision-making ● Leading projects and making decisions independently ● Co-design examples: training materials, new service, organisational policy, decision-making shared equally ● Co-production examples: developing and delivering together

LO2. Barriers and enablers in engaging people with lived experience in decision-making and policy

Enablers:

- Using clear and plain language
- Connecting on a human level
- Clearly explaining benefits people will get from participating

LO3. What does inclusive and meaningful participation mean to practitioners and participants themselves?

Practitioners:

- Achieve a clearer understanding of audience's needs
- Help staff develop a better understanding of mental health
- Projects and services meet the needs of a wide range of people more effectively
- Build credibility with the public and funders
- Promote initiatives to target audience
- Aim for longer-term participation

Participants:

- Help people contribute and feel connected to their local communities and different kinds of work
- Feel valued and respected
- Meet others with similar experiences
- Help develop key skills
- Support future employment
- Motivate participants to set up their own events or groups
- Connect people with projects that want to meet their needs

LO4. Impact/benefits on policy and decision-making of engaging people with lived experience

Link to document

<https://www.mind.org.uk/about-us/our-policy-work/sport-physical-activity-and-mental-health/resources/mental-health-and-physical-activity-toolkit/guide-3-involving-people-with-lived-experience-of-mental-health-problems-in-the-design-and-delivery-of-your-work/>



Case study 15: Are people with lived experience of poverty finally being heard?

<p>Organisation and authors</p>	<p>Poverty2Solutions Sarah Campbell</p>
<p>Year</p>	<p>2018</p>
<p>Purpose</p>	<p>A group of lived experience from across the UK came together to strengthen their voice and actions on poverty.</p>
<p>Why is this case study useful?</p>	<p>Blog post talks about a lived experience collective tackling poverty around the UK that managed to be heard across various media and government channels.</p>
<p>LO1. Best practices in engaging people with lived experience:</p>	<ul style="list-style-type: none"> ● Sharing power ● Building trust between bigger organisations and small groups ● Give a platform for those affected by an issue <p><i>“It’s not about giving voice. People have a voice - meet these groups and you will have no doubt about that! It is more about sharing power and platforms as organisations, building trust with these small yet formidable groups to form powerful alliances that connect the grassroots to the grass ‘tops.’” (Campbell)</i></p>
<p>LO2. Barriers and enablers in engaging people with lived experience in decision-making and policy</p>	<div style="background-color: #d9ead3; height: 150px;"></div>

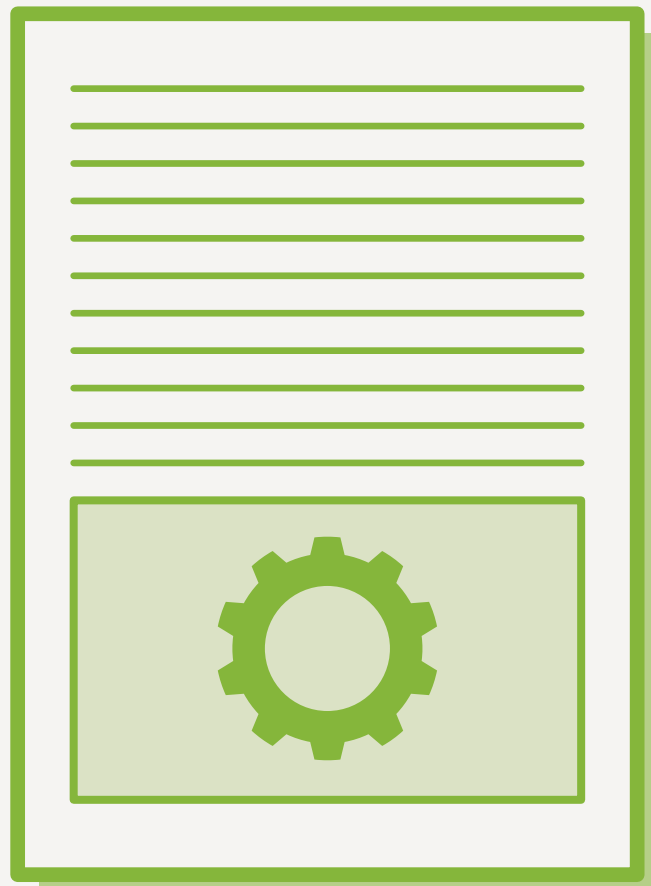
LO3. What does inclusive and meaningful participation mean to practitioners and participants themselves?

- Making civil society more diverse and ensure a platform for those affected

LO4. Impact/benefits on policy and decision-making of engaging people with lived experience

Link to document

<https://www.jrf.org.uk/blog/are-people-lived-experience-poverty-finally-being-heard>



Case study 16: Patient participation as an integral part of patient-reported outcomes development ensures the representation of the patient voice: a case study from the field of rheumatology

Organisation and authors	Maarten de Wit, Tore Kvien and Laure Gossec BMJ Journals
Year	2015
Purpose	<i>"Patient-reported outcomes (PROs) are important instruments to evaluate healthcare interventions, both in clinical practice and clinical research."</i> (p.1)
Why is this case study useful?	Detailed description on the ways in which people with lived experience were involved in the different stages of the research. Included a participation ladder in the Psoriatic Arthritis Impact of Disease (PsAID) development process. Brings forth further evidence on the benefits of patient involvement in research.
LO1. Best practices in engaging people with lived experience:	<ul style="list-style-type: none"> • Recognition of participation as a process; participation requires an ongoing, direct dialogue between patients and researchers; make patient participation an integral part of the project • Participation should be tailor made; no concept exists that fits all • Proportional representation of patients during team meetings as equal collaborators • Participation requires an additional effort in terms of time, energy and resources • Management of expectations is crucial

- Achieving representation of the patient's perspective requires multiple forms of participation in different phases and on different levels. Apart from having PRPs in the steering group, the input from PRPs may be broadened by adding surveys, interviews, focus group meetings, or Delphi exercises to the research design
- A structural approach guarantees sustainable partnerships between professionals and patients
- Willingness for mutual learning
- A deliberative and structured process- to enable patients to contribute in a meaningful way
- Peer researcher took part in all discussions and decision-making stages of the project
- Preserving the patient's perspective in the project
- Patients participated in analysis of data

(p.6).

LO2. Barriers and enablers in engaging people with lived experience in decision-making and policy

Barriers:

Tensions in how to organise, facilitate or design when the points of view or interests from people with lived experience and others like staff are different. This requires:

- Time and space for consensus
- Constructive attitude
- Facilitation that can deal with power imbalances
- Patient participation is still very tokenistic

Enablers:

- Financial resources to enable appropriate compensation of patient research partners

LO3. What does inclusive and meaningful participation mean to practitioners and participants themselves?

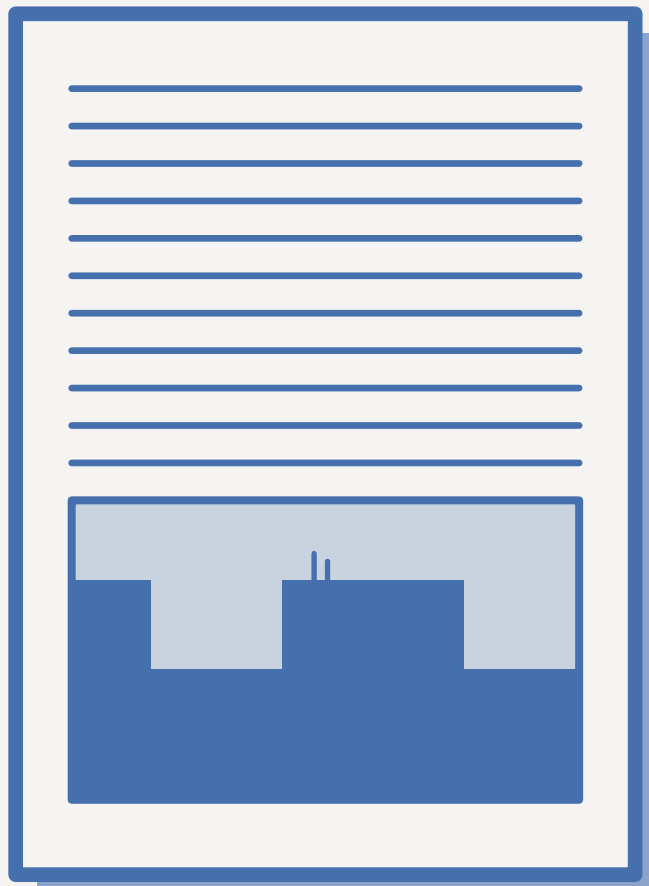
- Safe space to share stories and experiences

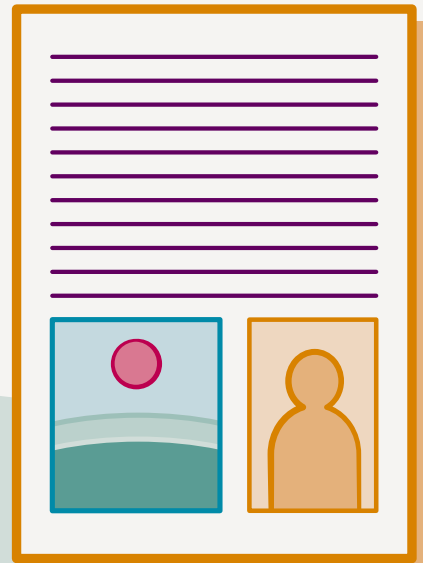
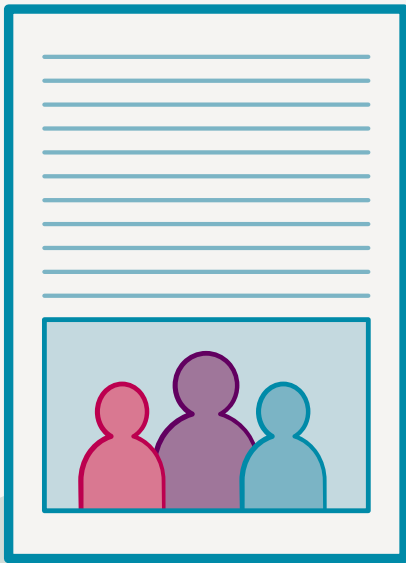
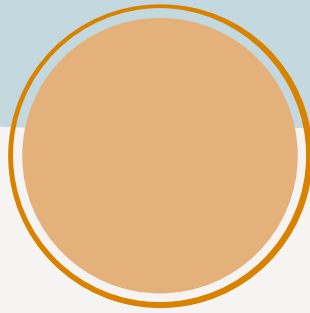
LO4. Impact/benefits on policy and decision-making of engaging people with lived experience

- Involvement of patient representatives in scientific projects has been useful for task force leaders developing management recommendations
- Including patient contributions at different phases resulted in an instrument with high face validity

Link to document

<https://rmdopen.bmj.com/content/rmdopen/1/1/e000129.full.pdf>





The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers.

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